

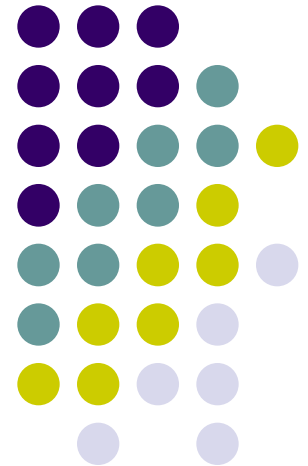
# **New Futures: Exchanging research knowledge about older LGBT communities**

Manchester Interdisciplinary Centre  
for Ageing (MICRA)

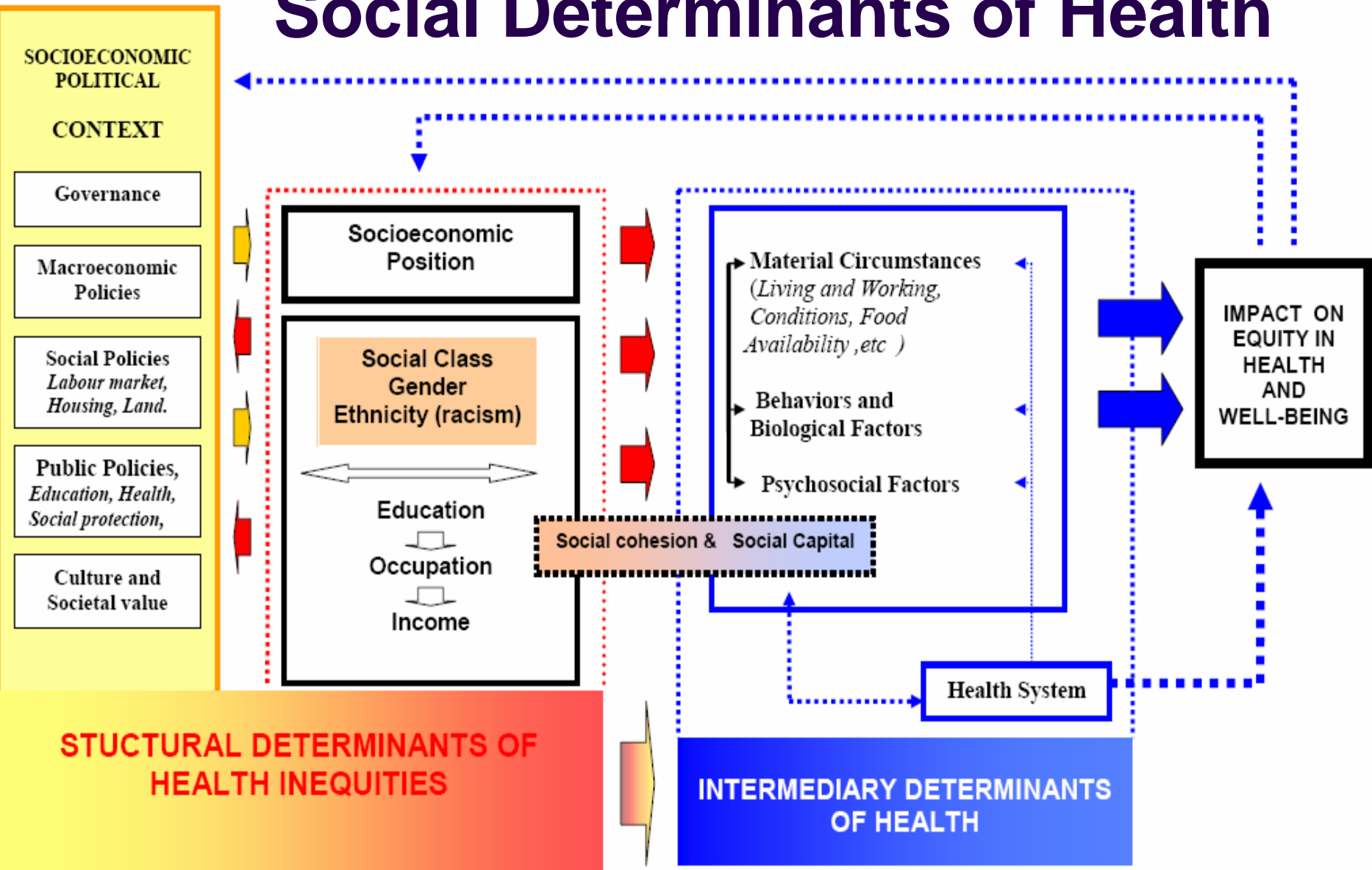
22 October 2014

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De Montfort University, Leicester.



# Social Determinants of Health



# Health / social policy for LGBT people



- Working for Lesbian, Gay, Bisexual and Transgender Equality: Action Plan 2011;
- Preventing Suicide in England – A cross-government outcomes strategy to save lives 2012;
- The route to success in End of Life Care – achieving quality for LGBT people 2012;
- A Framework for Sexual Health Improvement in England 2013
- Lesbian, Gay, Bisexual and Trans Public Health Outcomes Framework Companion Document 2013.
- Joint Strategic Needs Assessments in Health and Social care
- Care Act 2014;

# Understanding SDoH and LGBT people



- GB men over 50 most deeply affected by HIV/AIDS;
- Multiple losses and stigma;
- Creative users of social media;
- Some LGBT people have extensive social networks (e.g. Aronson)
- But they are two-and-a-half times as likely to live alone (LAT),
- Twice as likely to be single,
- Four-and-a-half times as likely to have no children to call upon in times of need
- Older GB men increased likelihood of psychological distress;
- Older LB women more likely to report poor/fair health, needing help with instrumental activities of daily living.

Gonzales, G. & Henning-Smith, C. (2014) Disparities in Health and Disability Among Older Adults in Same-Sex Cohabiting Relationships, *Journal of Aging Health* Sep 23. pii: 0898264314551332. [Epub ahead of print]



# Increasing integration of health and social care

- 1. Social care related quality of life;
- 2. Ensuring that people have a positive experience of care & support;
- 3. Delaying and reducing the need for care;
- 4. Safeguarding.



Adult Social  
Care  
Outcomes  
Framework

NHS  
Outcomes  
Framework



Public  
Health  
Outcomes  
Framework



- 1. Improving the wider determinants of health;
- 4. Preventing premature mortality

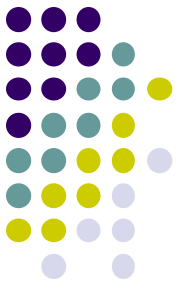
- 1. Preventing people from dying prematurely;
- 2. Enhancing quality of life for people with long-term conditions;
- 3. Helping people to recover from episodes of ill health;
- 4. Ensuring that people have a positive experience of care;
- 5. Treating and caring for people in safely and protecting

# Large-scale research among LGBT populations



- **2014 English General Practice Patient survey**
- **2010, 2011, 2013 Cancer Patient Experience Survey;**
- **2010 National Survey of Sexual Attitudes and Lifestyles;**
- **2008 Systematic review of mental disorder, suicide, and deliberate self harm in lesbian, gay and bisexual people.**

# Distinctive experiences of cancer care



Doctors never talked  
in front of patient as if  
they were not there

*Always treated with  
respect and dignity  
by hospital staff*

**Never felt treated  
as a set of cancer  
symptoms rather  
than as a whole  
person**

*Hospital staff  
always did  
everything they  
could to control  
their pain*

Patient was given information  
about support / self help groups  
for people with cancer

Differences on 16 domains  
where LGB people  
reported less favourable  
treatment



# Coming Out About Breast Cancer

Research on lesbian and bisexual women's experiences of breast cancer

## Lesbian and bisexual women and breast cancer

ESRC knowledge exchange programme RES-192-22-0111







# Steering group

- 3 LB women with breast cancer
- Head of Policy and Research, Breast Cancer Care.
- User inclusion manager, Macmillan.
- Public relations officer, Cancer Research UK
- Clinical projects manager, Metro centre, London.
- Development worker, Kairos (centre for health/well being).
- Academic, UCL.
- Nurse specialist, London regional cancer network
- NHS South West, Equality and Diversity Lead

# Epistemologies of LB women's lived experiences of breast cancer



- What does it mean to have breast cancer when your partner is a woman? How do LB women feel about the prospect of losing their breast? Are partners more or less empathic? Do they display more or less supportive behaviours?
- Subtle and nuanced understandings of the complex interplay of their identities, experiences and values in their everyday lives and in their interactions with providers of services;
- Decisions not to undergo breast reconstruction: they encountered attitudes based on heteronormative constructions of femininity from surgeons providing care;

Please donate

Search

Campaigning & volunteering

Campaigning

Policy

Breast cancer and inequalities

**Lesbian and bisexual women and breast cancer**

Black and South Asian women and breast cancer

Older women and breast cancer

Consultation responses

Policy reports

Volunteering

Breast Cancer Voices

What we do

Sign up to our newsletter for updates on what we do and how you can help.

## Lesbian and bisexual women and breast cancer

As part of our health inequalities work we published a policy briefing highlighting the experiences of lesbian and bisexual women affected by breast cancer. Research has shown that they have poorer levels of patient experience (due in large part to discrimination), less specialist services available, and little data collected about them as a patient group.

We hope our briefing document will be useful to:

- policymakers concerned with ensuring health and social care is responsive to all, regardless of sexuality (or other differences)
- healthcare professionals working to provide the best possible care for their patients
- cancer charities and other groups providing services to women affected by breast cancer, including those who are lesbian and bisexual
- LGBT community and voluntary groups concerned with health issues in their communities.

Our recommendations are aimed at improving services. We hope they will be useful to all groups wanting to take action on this issue.

Download a copy of our report below:

[Lesbian and bisexual women and breast cancer report \(PDF\)](#)

### Spotlight campaign



Improve care for patients with secondary breast cancer

[Get involved](#)

# Improving the LGBT cancer care pathway: the model of 'engaged scholarship'

## Impact

Policy briefing, *Lesbian and bisexual women with breast cancer*, produced by the charity;  
Key learning event with cancer professionals: case studies;  
Development of practice guidance: Supporting LGBT people with cancer.

## Use

Developing the organisational ethos: Equality and Diversity strategy, user audits of services, inclusive imagery and language,  
<http://www.breastcancercare.org.uk/campaigning-volunteering/policy/breast-cancer-inequalities/lesbian-bisexual-women-breast-cancer>

## Uptake

**Who?** Two national cancer charities; two LGBT VCS; an Equality and Diversity Manager in the NHS; academics specialising in cancer; and cancer service users and carers.

**What?** contributing to the application for funding, developing research questions, designing the project, analysing the data and communicating the findings (process impacts).

# Supporting LGBT people with cancer



- Equality and diversity audits
- Macmillan – seminar for cancer professionals
- Practice guidance



Developing  
professional  
knowledge  
about breast  
cancer in  
lesbian and  
bisexual women



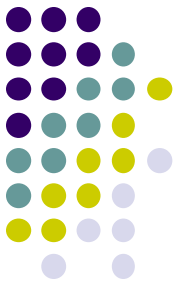
Knowledge exchange  
programme  
RES-192-22-0111

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

# What would cancer equality look like for LGBT people?



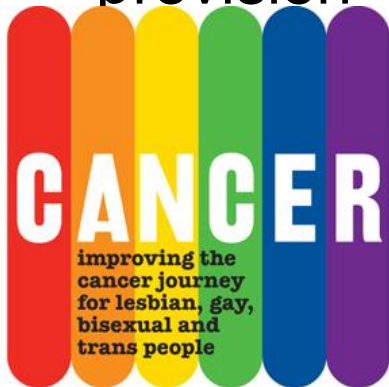
- Services would routinely consider LGBT people as a population of concern.
- Equality and diversity policy statements would specifically include LGBT people.
- Language used to describe LGBT people would not pathologise them.
- Data collection would routinely include sexual orientation and gender identity.
- Inclusion of LGBT people within health inequalities initiatives.



# Taking research forward

## Processes

- Working with stakeholders;
- Involving service users;
- Strategy for impact and embedding findings in provision



## Methods

- QualRes -developing theory
  - Queer Theory; Human Rights
  - Health Inequalities
- Mixed methods
- Developing sensitive tools
- Analysis of existing data sets.

# Topics And challenges



- Quality Of Life;
- Perceptions of ageing;
- Care and Support needs
- Social connectedness;
- Personalisation and direct payments;
- Residential care and housing choices
- Celebrating Intergenerational Diversity Among LGBT People.

- Intersectionality;
- Embedding equality;
- It's all over now!
- The numbers game
- Older Trans people



# Trans people's health and social care



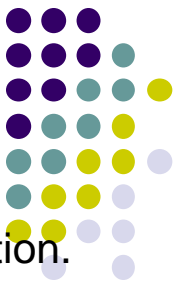
- Health was identified by respondents as being the top area of concern for the transgender community, with nearly half of respondents (49%) selecting this as their priority
- GEO transgender survey 2011
- Training of staff, research, suicide collaboration with voluntary sector

# Recent research on health and social care in Trans communities



- ***Mental health***
- ***Domestic abuse***
- ***Older trans people and residential care homes***
- ***Transphobic hate crime***
- ***Developing good practice in assessments of need and risk***

# References



- Boehmer, U., Miao, X., and Ozonoff, A. (2011) Cancer survivorship and sexual orientation. *Cancer*, 117: 3796-3804.
- Brown, J.P. and Tracy, J.K. (2008) Lesbians and cancer: an overlooked health disparity, *Cancer Causes and Control*, 19 (10): 1009-20.
- Burkhalter, J. Hay, J.L. Coups, E. Warren, B. Li, Y. and Ostroff, J.S. (2011) Perceived risk for cancer in an urban sexual minority, *Journal of Behavioral Medicine*, 34 (3): 157-169.
- Cancer Patient Experience Survey (CPES) (2010) *Cancer Patient Experience Survey Programme - 2010: National survey report*. London: Department of Health.
- Martin, S. (2010) 'Co-production of social research: strategies for engaged scholarship,' *Public Money & Management*, 30 (4): 211-218.
- McCormack, B. (2011) 'Engaged scholarship and research impact: Integrating the doing and using of research in practice,' *Journal of Research in Nursing*, 16 (2): 111-127.
- Mitchell, P. Pirkis, J. Hall, J. and Haas, M. (2009) 'Partnerships for knowledge exchange in health services research, policy and practice,' *Journal of Health Services Research & Policy*, 14 (2): 104-111.
- Nutley, S.M. Walter, I. And Davies, H.T.O. (2008) *Using Evidence: How research can inform public services*. Bristol: The Policy Press.
- Wilkinson, H. Gallagher, M. and Smith, M. (2012) 'A collaborative approach to defining the usefulness of impact: lessons from a knowledge exchange project involving academics and social work practitioners,' *Evidence & Policy*, 8 (3): 311-27.





LGBT Friendly Services



New book:



# Lesbian, gay, bisexual and trans health inequalities: International perspectives in social work

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De Montfort University  
and Kate Karban,  
University of Bradford

